



# **Medical Research and Innovation Priorities for 2020–2022**

A submission to the Medical Research Future Fund

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## **About Dementia Australia**

No matter how you are impacted by dementia or who you are, Dementia Australia is here for you.

We exist to support and empower the estimated half a million Australians living with dementia and almost 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia, yet it remains one of the most challenging and misunderstood conditions.

Founded by carers more than 35 years ago, today we are the national peak body for people impacted by dementia in Australia.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible.



## Introduction

Dementia Australia welcomes the opportunity to reflect on the current Medical Research Future Fund (MRFF) Australian Medical Research and Innovation Priorities 2018-2020, and their ongoing appropriateness to guide MRFF investments in health and medical research over the next 12 months operating under the current Strategy.

It is important that the current priorities align with research needs and that Australian Medical Research Advisory Board and MRFF continues to fund relevant priorities that improve research effectiveness, efficacy, quality and safety to deliver improved health outcomes and a sustainable health system for all Australians.

Dementia Australia largely supports the current priorities and sees them as remaining particularly important in the contemporary context.

## Key issues

Dementia Australia would like to raise the following key issues:

1. That while dementia is represented in the ageing and aged care mission it is imperative that specific attention is given to dementia both within and outside the aged care environment. There must be dedicated funding to explore dementia issues because while we know that dementia care is expected to be part of the aged care sector more broadly, it is clear that dementia is not yet core business.
2. That dementia data and experience in ATSI communities is still poorly understood and there should be close relationships with indigenous leaders to understand the most relevant issues for exploration.
3. That digital health intelligence has the potential to significantly impact people living with dementia, families and carers, whether in their own homes or in residential care; and a detailed consultation with consumers about priorities should be undertaken.
4. That comparative effectiveness research, especially as it pertains to services and programs for dementia, should explore how practice translates into quality dementia care as well as how to embed those learnings into system-wide change and monitoring.
5. That primary care research is especially sparse when it comes to the impact of primary care on diagnosis, post-diagnostic support and care of people living with dementia, families and carers.



6. That clinical research capacity should include structures that teach researchers how to engage with people with a lived experience of dementia from the pre-design phase to implementation.

7. That public health interventions need to have a joined up approach that spans multiple complex health conditions, including dementia.

8. That translational research infrastructure is imperative, especially when it comes to embedding research findings into tangible policy change. A good example of this need is the vast body of research on the over-use of antipsychotics on people with dementia but the ongoing overuse in practice.

In this submission, Dementia Australia would like focus primarily on two of the priority areas most relevant to the context in which we operate in, to meet the needs of people living with dementia, their families and carers.

<b>Priority</b>	<b>Why action is needed</b>	<b>How best addressed</b>
<b>Ageing and Aged Care Research</b> into the diseases of ageing and the means to prolong quality of life, including tackling cognitive decline and dementia, and compressing the period of intense morbidity in later years through biomedical discovery and health service innovation.	The intergenerational distortion ahead requires a concerted research focus on ageing Australians. Optimising the physical and cognitive health and wellbeing of older Australians is one of society's greatest challenges. It requires a multidisciplinary understanding of prevention, behaviour, biomarkers, disability and mobility, co-morbidity, models of care, consumer choice and care needs.	A significant investment to boost efforts in biomedical, medical technology and health services research into ageing and aged care. Such a mission would need to be responsive to any research-relevant outcomes from the Royal Commission into Aged Care Quality and Safety, of which the interim report is due in October 2019.
<b>Consumer-Driven Research</b> Conduct research that is driven by crowd-sourcing consumer priorities and purposefully connecting researchers to consumers with the intent	Sometimes there is a mismatch between what researchers want to research and the lived experiences, values and priorities of consumers, carers and clinicians.	Establish a program that can pair researchers to consumers, carers and clinicians and through a joint priority setting methodology design grant opportunities that enable



of enhancing evidence translation into every day clinical practice.

Partnerships in research design and practice can increase the translation of research evidence and illuminate new discoveries, transforming the healthcare experience and maximising the impact of research investment.

consumer-driven targeted research.

### **Do the current Priorities remain relevant in the contemporary environment for continuation for a further 12 months?**

The current priorities are relevant in the contemporary environment. Additionally though, a consideration of prioritising the specific impacts COVID-19 has had on ageing and aged care is recommended for research funding.

“There should also be an emphasis on COVID-19 research and pandemic research and management, and somewhere an inclusion of involvement with CALD communities.” – Person living with dementia

Dementia Australia has heard many accounts of the damaging affect COVID-19 has had on people living with dementia, their families and carers’ mental health and wellbeing.

In a recent survey by Dementia Australia, which 86 people impacted by dementia responded to, it was found that COVID-19 has had an impact on physical health, psychological health, cognitive health and overall wellbeing. The key findings were:

- Respondents reported a drop in their physical health.
- People reported feeling more anxious due to COVID-19 and some people reported exacerbated loneliness
- For people living with dementia, some people reported a decline in their cognitive health
- Families and carers are experiencing higher than usual levels of stress and fatigue.
- There was a drop is respondents reported overall wellbeing.



These findings indicate a need to explore the flow on affects that COVID-19 may have on people's quality of life, mental health and cognition.

"I am very social and enjoy the company of people. I believe that the dementia component of my disease progressed significantly" – Person living with dementia

Additionally, people impacted by dementia have shared with us that, while the current priorities are still relevant, it is important to ensure there are accountabilities put in place so they are implemented and appropriately measured.

"The priorities makes sense but there needs to be a call to action to make sure the "how best addressed" suggestions in the paper are put into action." – Person living with dementia

This also includes ensuring that all aspects of dementia are considered for inclusion in the ageing and aged care research priority, and that people impacted by dementia are empowered to participate in research and consultation processes.

"Every aspect – medical, physical, emotional, we need some support and research needs to be done into what can be done at the stages of early onset to keep quality of life." – Person living with dementia

"Where is the support? There is support for cancer, but there is absolutely nothing to keep me healthy. There is a lot of things on the emotional and physical side of it that could be done so much better." – Person living with dementia

"There needs to be further support of a holistic approach to care to minimise medication use – there is a powerful impact of natural remedies and music therapy." – Carer

## **Should any of the Priorities be emphasised or de-emphasised for the next 12 month period?**

It is important to emphasise supporting programs that empower consumer participation in system reform, service delivery and individual decision-making. It is generally accepted that consumer participation improves health outcomes and gives weight to governance and planning decisions. On an individual level, tools that



enable consumers to take control and ownership of their health, such as advance care directives, could be a key feature.

“Although all priorities are important, the three areas that I believe require emphasis are: 1. Ageing and Aged Care 2. Consumer-Driven Research 3. Primary Care Research.” – Person living with dementia

“I think there should be emphasis on 'Ageing and Aged Care Research into the diseases of ageing and the means to prolong quality of life including tackling cognitive decline and dementia...' This an area of growing interest and concern. There is a need to improve the health, not only of the ageing population and for those people living with dementia in the community but to also improve the standard of care in aged care facilities for all people.” – Person living with dementia

Dementia Australia feels it is important that a diverse group of perspectives are sought when involving consumers (or advocates) in research. Diversity and variety in research is important to gain a wide range of perspectives that is more representative of the lived experience. There is a risk that the same people participating and responding to multiple opportunities can limit the richness of information and create a skewed view of key issues.

There is also a need to build the capacity in this space, so that both consumers and researchers have the skills needed to meaningfully involve consumers in research. A solution to this could be prioritising training as a means of addressing the ageing and aged care research priority.

Most researchers are aware that to get funding in the current context, consumer perspectives must be sought. However, the whole process needs to be adequately supported to avoid tokenism i.e. researchers need to see the value of involving advocates in their work.

“For research to be meaningful there is a need to involve consumers in all levels of research, in informing researchers of research areas needs, in developing research proposals, in the research itself and in informing the general public about research outcomes.” – Person living with dementia

Sustained investment in dementia research is needed, encompassing risk reduction, care at all stages of the disease, and the search for effective curative treatments. The investment must support the translation of research into practice, to ensure that people with dementia and their families benefit through improved care and services.





There is also a need to ensure that people with dementia, their families and carers continue to have a strong voice in how research is prioritised and implemented.

Additionally, a number of people impacted by dementia shared with us that they feel a focus on the holistic aspects of care should be emphasised within the research priorities.

“A focus on holistic aspects of dementia, not just medication.” – Person living with dementia

“Need for more information at the point of diagnosis and clear pathways for holistic support and care. I want to be informed how the medical aspects affect me, then let me make a decision, not make it for me.” – Person living with dementia

There is also support for a greater emphasis on global health and health security, and Aboriginal and Torres Strait Islander Health.

“Given the pandemic, the disproportionate impact that has had on the ageing population, as well as the Royal Commission into Aged Care. I believe Global Health and Health Security and Ageing and Aged Care should be given the highest priority, along with Aboriginal and Torres Strait Islander Health.” – Former carer

“In 'Aboriginal and Torres Strait Islander Health....' There is a need for specific dementia research and in working with Aboriginal and Torres Strait Islander people to develop meaningful research and outcomes.” – Person living with dementia

### **Are there unaddressed gaps in knowledge, capacity and effort across the healthcare continuum and research pipeline that would warrant changes to the Priorities?**

There are not necessarily gaps that warrant changes to the priorities, but rather there are opportunities for collaboration to ensure consumer involvement in research is seriously considered and opportunities made available for meaningful participation. For clarity, 'being involved' in the decision making aspects of research means people living with dementia and care partners work together with the research team.

For example, identifying research priorities, being a co-researcher, sitting on steering committees, providing guidance in the preparation of materials to be used with



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participants living with dementia, reviewing surveys/questionnaires and other printed material, evaluation and dissemination of research. While ‘participation’ in research is being a subject of the research. For example participating in a clinical trial, filling out a survey or being interviewed.

“People with dementia being involved in research at every stage.” – Person living with dementia

Specifically, the Dementia Centre of Collaborative Research is looking to develop their own program of consumer involvement. Without the National Institute for Dementia Research (NNIDR), there is a need to have someone keep track of all these initiatives. It would be beneficial to include this in the “how best addressed” component of the ‘Ageing and Aged Care’ priority so the program could provide oversight for meaningful consumer participation.

There are numerous documents and resources that outline the benefits of and approaches for the inclusion of people living with dementia and care partners in the decision-making aspects of research. A few examples include:

- Becoming involved in research: A guide for people living with dementia, their care partners and family members (2020) NNIDR.
- Statement on Consumer and Community involvement in Health and Medical Research, National Health and Medical Research Council (2016), Consumers Health Forum of Australia.
- Toolkit for Consumer and Community Involvement in Health and Medical Research (2020) NHMRC
- HCI (Human Computer Interaction/Interface) and Design in the Context of Dementia, (2020) Editors Brankaet and Kenning (The first five articles outline techniques for working with people living with Dementia from beginning to end)<sup>1</sup>.
- Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement) (2017) Aging & Mental Health Journal.

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<sup>1</sup> <https://link.springer.com/book/10.1007%2F978-3-030-32835-1> Section 5 Approaches for Authentic Engagement: Younger Onset Dementia includes 4 Dementia Advocates as Co-Authors.



However, there are gaps in making this a sustainable reality, and there is growing concern that consistent advocacy, adequate capacity and a clear focus is needed to ensure that the inclusion of people living with dementia and care partners in the decision-making aspect is embedded into the practice of research.

Additionally, there is a need for more education, particularly around the ageing needs of people living with dementia, their families and carers. Moreover, it is important to address translation of existing research into practice, as this is a key barrier – especially addressing the challenge of low understanding and awareness of dementia among the health workforce, particularly in the palliative and end of life stages.

“Primary health practitioners, as identified in the paper, are lacking in knowledge around cognitive impairment and dementia. Primary Care Research addresses this in part, but this is a very real weakness in the system, that requires attention.” – Person living with dementia

“Please consider doing research into how would educating Australians on ageing and cognitive function improve care and inclusion in the future.” – Former carer

“Doctors need to know more about dementia at the point of diagnosis and then let me make a decision about my care.” – Person living with dementia

“There just isn’t support for dementia like other conditions.” – Person living with dementia

Research needs to be able to facilitate answers to the full spectrum of social and clinical challenges, from dementia causes, to risk reduction and prevention, the impact of dementia on carers and family, quality of life issues, social isolation, disease management, care, treatment and ultimately, a cure. This includes ensuring there is no miscommunication around the preventative messaging around dementia. Healthy lifestyle choices may reduce risk, however are not a guarantee for avoiding dementia. Some people impacted by dementia have shared with us that over simplistic messaging around prevention or risk reduction can lead to an implication that a person with a diagnosis of dementia is at fault for not reducing their risk. The fact remains that dementia is a devastating disease which affects many people from a wide range of backgrounds.



“In particular, I would prefer to see studies which investigate whether targeted exercise programs and nutritional advice can help alleviate the symptoms of those who have already been diagnosed with dementia.” – Former carer

With no currently available treatment that will significantly delay or treat dementia, and given the increasing burden to the health system that dementia represents, priority needs to be given to continuing and new dementia research investments from diagnosis to end of life. This includes looking at holistic approaches to care specific research into improving quality of life for those living with dementia.

“As a priority – every natural – go back to basics, let’s research it more.” – Carer

“A holistic approach to care has worked wonders with my mum. For example the use of turmeric has allowed her to avoid medications as it is an anti-inflammatory, anti-depressive, anti-bacterial, anti-oxidant alternative to medication.” – Carer

### **Is there an opportunity to consolidate the Priorities for the remaining twelve months of the Strategy?**

The priorities remain relevant and important, and Dementia Australia does not see the need for the consolidation of the priorities; however, there are synergies between some of the priorities that could be acknowledged and explored. Specifically the relationships between the Ageing and Aged Care with Global Health and Health Security; Aboriginal and Torres Strait Islander Health could be strengthened.

“I feel that the Ageing Health and Health Security could be partnered with the Aboriginal & Torres Strait Islander Health.” – Person living with dementia

“I think several seem to broadly come under the three priorities mentioned above (Global Health and Health Security; Ageing and Aged Care; and Aboriginal and Torres Strait Islander Health).” – Former carer

Additionally, we strongly urge the MRFF Board to consider a sustained investment in dementia research, to be aligned with current and future MRFF Roadmap priorities.

We also suggest that government work with philanthropic groups or other organisations to leverage/match funding. This would enable larger and/or more projects to be funded and facilitate the translation or implementation of evidence-based research into practice.



## Conclusion

Research into prevention, early intervention, treatment, and system responses will help equip Australia to meet the challenges that a steady increase in dementia prevalence will present to our primary health care, hospital, aged care, disability, and community care systems. We trust that the matters raised through our submission will be useful in helping the Australian Medical Research Advisory Board determine funding priorities for the MRFF and welcome the opportunity to discuss our submission with you further.